ORDER:
Restricting the publication of any report of the matter which disclosed the deceased's name and the names of any of her carers and/or anything that may identify the carers.

CITATION: *Inquest into the death of Miss M* [2013] NTMC 031

TITLE OF COURT:	Coroner's Court
JURISDICTION:	Katherine
FILE NO(s):	D0039/2013
DELIVERED ON:	18 December 2013
DELIVERED AT:	Katherine
HEARING DATE(s):	17 December 2013
FINDING OF:	Mr Greg Cavanagh SM
CATCHWORDS:	**Death in care, natural cause death, care and treatment exemplary**

REPRESENTATION:

Counsel:

Assisting:	Jodi Truman
Department of Children and Families:	Gabby Brown

Judgment category classification:	A
Judgement ID number:	[2013] NTMC 031
Number of paragraphs:	56
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IN THE CORONER'S COURT
AT KATHERINE IN THE NORTHERN
TERRITORY OF AUSTRALIA

No. D0039/2013

In the matter of an Inquest into the death of
MISS M
ON 23 MARCH 2013
AT 1 BURNET COURT, KATHERINE EAST, KATHERINE

FINDINGS

Mr Greg Cavanagh SM

Introduction

1. "Miss M" (whose name has been restricted from publication) was an Aboriginal female born on 19 January 1998 at the Gove District Hospital, in Nhulunbuy in the Northern Territory of Australia. Her mother is Mandy B and her father is Desmond M (deceased). At the time of her birth, the family were from Umbakumba on Groote Eylandt in Eastern Arnhem Land.

2. Miss M died sometime between 7.00 pm and 7.43 pm on 23 March 2013 at her home in Katherine East in the Northern Territory of Australia. She was declared deceased at the Katherine Hospital by Dr Leslie at 8.35 pm after cardio pulmonary resuscitation ("CPR") was ceased. Miss M was 15 years of age at the time of her death.

3. For reasons which will appear below, this death was reportable to me pursuant to s.12 of the *Coroners Act* ("the Act") because it was a death of a person who immediately before death was a "person held in care". A person held in care is defined under s.12 of the Act to include a child who is in the CEO's care as defined in the *Care and Protection of Children Act*. As a result of being a person held in care immediately prior to death, this inquest is mandatory pursuant to s.15(1) of the Act.

4. Counsel assisting me at this inquest was Ms Jodi Truman. Ms Gabby Brown was granted leave to appear for the Department of Children and Families. There were no other formal appearances however I note that Miss M's carers, namely Mr E and Ms E were in attendance at this inquest, together with Miss M's school principal, her teacher and a lady from NT Friendship and Support Services. I thank all of those individuals for the respect that they showed during the course of the evidence surrounding the death of Miss M who was clearly very loved and cared for by all of them.

5. The Coroner's Court can impose certain restrictions on the publication of reports of the proceeding. The power to do so is found in s43 of the *Act* as follows:

> "43. Restriction on publication of reports
>
> "(1) A coroner shall order that a report of an inquest or of part of the proceedings, or of evidence given at an inquest, shall not be published if the coroner reasonably believes that, to publish the report, would -
>
> (a) be likely to prejudice a person's fair trial;
>
> (b) be contrary to the administration of justice, national security or personal security; or
>
> (c) involve the disclosure of details of sensitive personal matters including, where the senior next of kin of the deceased have so requested, the name of the deceased.
>
> (2) A person shall not publish a report in contravention of an order under subsection (1).
>
> Penalty for an offence against this subsection: $10,000 or imprisonment for 2 years."

6. In these proceedings, I made an order restricting the publication of any report of the matter which disclosed the deceased's name and the names of any of her carers and/or anything that may identify the carers. That order remains in place.

The Conduct of this Inquest

7. Five (5) witnesses were called to give evidence at this inquest. Those persons were:

   7.1 Ms Angela Brannelly, General Manager at the Katherine Hospital ("KH");

   7.2 Detective Acting Sergeant Anastacia Cutler, the Officer in Charge of the Coronial Investigation ;

   7.3 Ms E, female carer of the deceased at the time of her death;

   7.4 Mr E, male carer of the deceased at the time of her death; and

   7.5 Ms Stephanie Fielder, Regional Executive Director of the Katherine and Northern Region of the Department of Children and Families ("DCF").

8. A brief of evidence containing various statutory declarations and numerous other reports, police documentation, and records were tendered into evidence ("exhibit 2"). I also received into evidence the numerous original medical files (exhibit 3), the records held by DCF (exhibit 4), the file of NT Friendship and Support Services (exhibit 5) and her education records (exhibit 6).

9. Pursuant to s34 of the Act, I am required to make the following findings:

   "(1) A Coroner investigating:

      a. A death shall, if possible, find:

      (i) The identity of the deceased person.

      (ii) The time and place of death.

      (iii) The cause of death.

(iv) Particulars required to register the death under the *Births Deaths and Marriages Registration Act*"

10. I note that section 34(2) of the *Act* also provides that I may comment on a matter including public health or safety connected with the death being investigated. Additionally, I may make recommendations pursuant to section 35 as follows:

> "(1) A Coroner may report to the Attorney General on a death or disaster investigated by the Coroner.
>
> (2) A Coroner may make recommendations to the Attorney General on a matter, including public health or safety or the administration of justice connected with a death or disaster investigated by the Coroner.
>
> (3) A Coroner shall report to the Commissioner of Police and Director of Public Prosecutions appointed under the Director of Public Prosecutions Act if the Coroner believes that a crime may have been committed in connection with a death or disaster investigated by the Coroner"

Background medical history and involvement of DCF

11. At the time of her death Miss M was fifteen (15) years of age. She was born at the Gove District Hospital and at the time of her birth was diagnosed as having microcephaly, which is a condition of having an abnormally small head or cranial capacity. At seven months of age she showed moderate levels of Cytomegalovirus (CMV).

12. I received evidence that Cytomegalovirus infection is a common viral illness and infection is usually without symptoms but occasionally, symptoms similar to glandular fever can occur. The most severe form of the disease can however cause severe damage to the brain and liver. When the signs of

CMV were found, Miss M was reported to be suffering developmental delay and failure to thrive.

13. On 16 September 2000, Miss M was admitted to the Royal Darwin Hospital (RDH) suffering from fever. She was diagnosed as suffering from Acute Disseminated Encephalomyelitis (ADEM). I received evidence that this is a disease of the brain characterised by a brief but widespread attack of inflammation (swelling) in the brain and spinal cord that damages the protective covering of nerve fibres. It typically damages white matter (brain tissue) leading to neurological symptoms. Miss M was then only 2 years of age.

14. ADEM is most common in children, and most make a full recovery. In fact when Miss M was eventually discharged from hospital she was sitting independently, walking with both her hands held, was able to speak a few words and could use her hands to play.

15. Unfortunately however, Miss M developed a second bout of ADEM when she was 5 years of age in 2003 and this caused profound brain injury. She was hospitalised for 7 months at Royal Darwin Hospital and was diagnosed then with spastic quadriparesis and global developmental delay with extensive cystic white matter changes and multiple areas of atrophy, permanent lesions and damage to her brain. She was left severely and multiply disabled with nil control of physical movement, nil language, global developmental delay and fully dependent for all her care needs. Miss M was unable to feed orally and therefore she underwent a gastrostomy, which is a surgical procedure for inserting a tube through her abdomen wall and into the stomach for feeding and drainage.

16. Miss M was seen by various medical professionals in various places, including Royal Darwin Hospital, Katherine District Hospital, Gove District Hospital, Umbakumba Health Clinic and Wurli Wurlinjang Clinic. Those

records were tendered into evidence before me and show that Miss M had the following medical diagnoses:

16.1 Spastic Quadriplegia – severe cerebral palsy;

16.2 Epilepsy;

16.3 Fixed flexion contractures;

16.4 Constipation;

16.5 Severe Equinovarus Foot Deformity;

16.6 Severe Scoliosis;

16.7 Restrictive Lung Disease;

16.8 Gum and Palate Hypertrophy; and

16.9 Severe dental caries.

17. Paediatrician, Dr Louise Woodward, who was the last paediatrician to treat Miss M described Miss M's medical circumstances in her statement to the police as follows:

> "(Miss M) was a severely disabled 14 year old girl when I met her. She had severe cerebral palsy secondary to repeated episodes of brain inflammation (acute disseminated encephalomyelitis). Her Gross Motor Classification Score was a level of 5, which indicated that she had the most severe level of disability possible. She had complete reliance on carers to attend to every aspect of her activities of daily living, and a complete inability to mobilise independently. She required a wheelchair with special supports to help her sit up. …
>
> She required complicated orthotics to prevent and manage contractures of her limbs which occurred due to her abnormally tight muscles secondary to her brain damage (cerebral palsy). These contractures caused (Miss M) a great deal of discomfort, especially in her right ankle. The only option to reduce the pain of her right ankle was to amputate her right foot but she was not able to have the surgery due to the high risk of an anaesthetic.

(Miss M) had a PEG (Percutaneous Endoscopic Gastrostomy) tube to deliver feeds as she was unable to swallow or chew effectively. She had constipation which was most likely secondary to her disability and caused her discomfort. She also had epilepsy due to the damage to her brain involving frequent seizures which were difficult to control. She had about 4-6 seizures per day.

(Miss M) had severe scoliosis (spine curvature) due to her weak muscles secondary to her cerebral palsy (brain damage). This severe scoliosis was progressively compressing her lungs and restricting their function. She had increasingly difficult breathing and was pre-disposed to serious lung infections. This was combined with severe gum hypertrophy where her gums thickened to such an extent that she had difficulty breathing air into her lungs. This in turn is most likely to have caused strain on her heart and lungs. The only option for alleviating her symptoms of lung restriction due to the scoliosis was complicated and difficult orthopaedic surgery to straighten her spine. Again, due to the high risk of anaesthesia in this child and the likely poor outcome of the surgery, she was not considered for such a procedure. She most likely also had pulmonary hypertension (raised pressures in her lung vessels) caused by her scoliosis and lung restriction. This causes her oxygen levels to drop if she becomes anxious or distressed and is ultimately a fatal condition if the underlying cause is not treated. In her case, the underlying cause could not safely or ethically be treated.

(Miss M) had significant dental caries (holes) and gingivitis (gum infection) as her teeth were very difficult to brush due to her gum abnormalities. This also caused her significant discomfort. …".

18. As can clearly be seen by the above I find that Miss M had significant and extremely complicated medical issues.

19. On or about 28 August 2007, when Miss M was only 9 years of age, the Department of Children and Families ("DCF" as it is now known) received a child protection report about Miss M. It appears her condition had deteriorated significantly following recurrent bouts of pneumonia. Her grandparents, who were her main carers, had passed away within months of each other and her weight was assessed as dangerously low due to her being malnourished. The notification was investigated and DCF became involved in her care arrangements.

20. Despite attempts by DCF to keep Miss M in her community at Umbakumba, on 6 December 2007 the family acknowledged their inability to care for Miss M and requested she be placed outside of the community where she could be better cared for and supported. As a result she was placed in the care of DCF under a Temporary Custody Agreement which was continued a number of times and placed with NT Friendship and Support Services in Katherine. Miss M had previously spent respite time with this organisation and had developed a relationship with the carer. Those carers were Ms E and Mr E.

21. DCF continued their involvement in the care of Miss M and she was enrolled at Kintore School and was doing well. She was reported as being happy and healthy and participating in various activities to the best of her ability.

22. On 28 October 2008 however Miss M was returned to the care of her mother following meeting with DCF, the Umbakumba Women's Centre and Aged and Disability Services. DCF then closed its case and there appears to have been no further issues for some time except for a report in 2010 which was investigated by DCF and determined no action was necessary as family had intervened.

23. DCF became involved again however on 23 February 2011 and Miss M was removed from the care of her grandfather and admitted to hospital. It appears that her mother had not been contactable for the previous 9 weeks after leaving to go to Darwin to drink and her grandfather was too ill to care for her. Miss M was returned to her mother but DCF continued its investigations and on 5 May 2011 another family meeting was held at which time a decision was again made by the family that they could not care for Miss M and her needs would be best met by a carer.

24. On 29 June 2011 Miss M's mother signed a Temporary Custody Agreement and Miss M was again placed with NT Friendship and Support Services in

Katherine. On 22 March 2012 after difficulties in contacting family, including her mother, Miss M was eventually made the subject of a Protection Order with long term parental responsibility granted to DCF until she turned 18 years of age.

25. Miss M was in fact placed once again in the care of Ms E and Mr E on or about 6 June 2011 and remained in their care until she died. It is clear that both Ms E and Mr E are two remarkable and caring individuals who agreed to take Miss M into their care despite her needs being incredibly high. As I said during the course of this inquest, they deserve to be commended for the care they provided to Miss M. Whilst in their care, Miss M went to school at Kintore and participated as best she could.

26. Miss M's health however was frequently threatened due to her respiratory problems. On 25 May 2012 Miss M was admitted to Katherine District Hospital as a result of a viral infection. She had difficulties breathing and was at risk of going into respiratory arrest. Her condition was life threatening. Concerns were reported by medical staff in relation to her life expectancy and she was referred to palliative care. However Miss M recovered and on 30 May 2012 she was discharged.

27. Because of the concerns as to her life expectancy and instability of her health, further investigations were carried out by DCF as to the most appropriate way to manage her care. On 5 September 2012 an Advance Care Directive ("ACD") was entered into. This ACD was developed in consultation with the senior family members of Miss M, including her mother and grandfather. I received a copy of the ACD which was signed by her grandfather and provided that the following directions be followed:

    - "If my Grand-daughter (Miss M) is acutely ill and unable to communicate responsively with her family and friends, and it is reasonably certain that she will not recover, I want her to be allowed to die naturally and be cared for with dignity.

- I do not want her to be kept alive by extraordinary burdensome measures (e.g. CPR). If any of these treatments have been started, I want them stopped. However I do want palliative care that includes medications and other treatments to alleviate suffering and keep her comfortable and for her to be offered something to eat and drink."

28. I received evidence from Dr Louise Woodward via her statement to the police that she too was in agreement with the ACD:

> "… due to the terminal nature of (Miss M's) medical problems and the futility of heroic treatment".

29. That ACD was approved by the Chief Executive of DCF on 8 November 2012, but was stated to be subject to the following:

> "Approve medical non-intervention for (Miss M) in accordance with treating medical practitioner's advice and the Advance Care Directive attached".

Events leading up to the death

30. On 12 March 2013 Ms E travelled to the Philippines because of a death in her family. As a result, Miss M was placed in the temporary care of another carer from NT Friendship and Support Services. I received evidence via the medical documents that whilst Miss M was in this temporary arrangement she was taken to the Wurli Wurlinjang Clinic by her temporary carer on 20 March 2013. Miss M was noted to have a possible infection around her PEG site and the carer was concerned that she was more sleepy than usual.

31. Staff at the clinic referred Miss M and her carer to the Katherine Hospital that day and she was seen in Accident and Emergency. It is noted in the KH records that Miss M appeared "content" and that her PEG site was "oozing", but otherwise it was "non-inflamed" and appeared to be in the "normal position". Miss M was provided with antibiotics with a review scheduled for the next day, together with an ultrasound.

32. On 21 March 2013 Miss M's carer took her to the KH once again. At that stage it was noted that Miss M had vomited twice the night before but that she had managed two (2) feeds that day and there and been no vomiting. The carer did not however that Miss M had developed a "cough" which appeared to have started on 20 March 2013.

33. Miss M was examined at the KH and a chest x-ray was also taken. There was no obvious "consolidation" (i.e. an indication of a possible infection) on the x-rays and Miss M was allowed to leave with the plan to review her when necessary. Miss M was then returned to her usual carers Ms E and Mr E at about 5.30pm that day. Both Ms E and Mr E reported that when Miss M was returned to their care they noted that she appeared to be coughing and wheezing, but that she appeared "happy". It appears they had no particular concerns for her and knew her circumstances well.

34. On Friday 22 March 2013 Miss M did not go to school as she had not slept well the night before due to coughing and wheezing. On Saturday 23 March 2013 she was reported as suffering from a build-up of phlegm but again her carers were attending to her and did not consider her condition beyond their capabilities and experiences in the past.

35. That day Ms E tended to Miss M's needs and fed her. She watched television and then had her usual sleep in the afternoon until about 6.00pm. At about 7.00pm Ms E flushed out the PEG and fed the deceased once again. Miss M was left in the company of two other children in the lounge room watching television whilst Ms E attended to household chores.

36. Sometime after 7.30pm Ms E entered the lounge room to check on the children and found that Miss M was not breathing. She screamed out for the assistance of Mr E and 000 was called. That call is recorded as being received at 7.44pm. The couple performed CPR until St John Ambulance ("SJA") arrived at 7.51pm and then took Miss M to the hospital. Miss M is recorded as arriving at the KH at 8.13pm.

37. According to the records tendered before me, SJA staff noted that there was "no carotid pulse, no apical heartbeat, no signs or sounds of respiration" and she was "asystole" when placed on the monitors (i.e. there was no cardiac electrical activity). Upon arrival at the KH it was recorded that there was "nil signs of life" with no spontaneous breathing and "nil pulse, asystole". CPR was continued at KH.

38. An attempt was made to intubate Miss M but this was unsuccessful due to "extensive palate hypertrophy". Miss M's larynx was eventually able to be viewed and it was discovered that it was obstructed by gastric contents and severe palate hypertrophy causing aspiration of food content. CPR was continued for 25 minutes with one shock also attempted. Contact was made with consultants at the RDH and a decision made to cease CPR. Throughout this time Miss M remained unconscious and without any signs of life. She was declared deceased at 8.35pm on 23 March 2013.

Cause of Death

39. There was no autopsy performed following this death. This decision was made following consultation with Dr Charles Leslie of KH who confirmed that it was his opinion that an autopsy was unnecessary and that the condition leading directly to the cause of death was cardiac and respiratory arrest as a result of pulmonary aspiration.

Issues for consideration

<u>The Advance Care Directive (ACD)</u>

40. As outlined earlier, there was an Advance Care Directive (ACD) in place at the time of this death. This provided, amongst other things, that the family did not wish for her to be kept alive by "extraordinary or overly burdensome measures" which specifically included CPR and that "if any of these treatments have been started" then the family wanted "them stopped".

41. It is clear that CPR was commenced upon Miss M by her carers, continued by the SJA crew and was carried on by medical staff at KH for a further 25 minutes post her arrival at the hospital. It is clear from the evidence that the ACD was not something discovered by KH staff until much later. I will return to this issue in a moment.

42. Whilst I accept that the carrying out of CPR was contrary to the very clear and specific terms of the ACD signed by the family, I also note that such ACD was subject to the words "in accordance with treating medical practitioner's advice".

43. I accept the evidence of Ms Brannelly that where there are acute events, such as those that occurred in this case, then intervention or resuscitation will be given en route to the hospital to preserve the best outcome for the child whilst the nature of the event is determined. In my opinion this is plainly common sense.

44. I also accept Ms Brannelly's evidence that Miss M had a possible obstruction to her airway and this could have been easily treatable. It would be inappropriate in those circumstances if something as simple (and potentially easily treatable) as that were simply ignored and no treatment given whatsoever because of the terms of an ACD. Further, in order for the "treating medical practitioner" to give advice, it would be necessary for treatment such as CPR to be given initially so that appropriate assessments could be made. Again, it appears to me that this is simply common sense.

45. I do not criticise those involved in the attempts at CPR of Miss M. I consider her carers were very loving to Miss M and would have wanted to do all that they could for her when they commenced CPR at home. I accept that SJA were simply carrying out their duties to the best of their abilities with the information that they had. I also accept that the medical staff at KH were attempting to carry out assessments of the patient and to keep her

alive whilst they did that. The actions of all of them are understandable and appropriate.

Failure to properly document the ACD

46. As noted above, the ACD was not something discovered by KH staff until after Miss M was pronounced deceased. I received evidence that the ACD was found to have been kept in the correspondence section of the KH file for Miss M. I received evidence that whilst it is the policy of the Department of Health that the ACD is kept in the correspondence section, it is usual practice to staple the ACD to the inside cover of the file so that it is easily located.

47. I note however that since this death occurred, education has been provided by Katherine Hospital to its emergency staff as to the importance of ensuring that:

47.1 All Advance Care Directives and documented care plans for children requiring non-intervention are kept at the front of the hard copy medical record file for early and quick reference at all times (including for emergency admissions); and

47.2 All discussions with a guardian or substitute health care decision maker of a child regarding non-intervention are clearly documented in the patient notes, including any meeting discussions between the paediatrician and the guardian, contents of those discussions, any concerns raised, and outcomes reached after discussion, including the documented care plan.

48. I am pleased to hear that such education has been provided without requiring recommendations to be made by myself. I consider the action taken by the KH in this regard to be appropriate and proactive to the issue identified concerning the ACD.

Missed paediatrician appointments

49. During the course of the evidence it was revealed that prior to her death; Miss M had missed two (2) paediatrician appointments on 22 January and 19 March 2013. Whilst it was disappointing to hear that these appointments were missed it is clear upon the evidence that it is certainly not the case that Miss M was not seeing any medical professionals in this time.

50. In fact, on the evidence it is clear that in relation to the paediatrician appointment missed on 22 January 2013, Miss M was in fact in Darwin on 23 January 2013 being seen by a special needs dentist, namely Dr Andrew Lee at the RDH, in relation to a possible dental procedure that her paediatrician had recommended be considered to try to improve Miss M's upper airway (see folio 23 of exhibit 2).

51. In relation to the paediatrician appointment missed on 19 March 2013, I note that this was during a period where Miss M's usual carer, namely Ms E, was overseas and Miss M was in the temporary care of another person. It is also clear from the evidence however that the temporary carer took Miss M to the Wurli Wurlinjang Clinic and then the KH on 20 March 2013, at which time she was examined and assessed by medical staff. I am confident that if there had been something of significant concern about Miss M's health at that time, then the medical practitioners involved would not have allowed Miss M to simply leave the KH and I note that she in fact returned the very next day on 21 March 2013 for a review.

52. In these circumstances whilst the appointments were missed, there is simply no evidence to suggest that the care being provided to Miss M was inappropriate or inadequate in any way and I do not consider that such missed paediatrician appointments have any relevance to Miss M's death.

Formal Findings

53. On the basis of the tendered material and oral evidence received at this Inquest I am able to make the following formal findings:

i. The identity of the deceased person was Miss M born 19 January 1998 at the Gove District Hospital, in Nhulunbuy in the Northern Territory of Australia.

ii. The time and place of death was approximately 8.35pm on 23 March 2013 at Katherine District Hospital after CPR was ceased following the deceased being found not breathing and unresponsive at her home in Katherine in the Northern Territory of Australia.

iii. The cause of death was cardiac and respiratory arrest following pulmonary aspiration.

iv. Particulars required to register the death:

a. The deceased was a female.

b. The deceased's name was Miss M.

c. The deceased was of Aboriginal descent.

d. The death was reported to the Coroner.

e. A post mortem examination was not carried out with the consent of the Coroner's office.

f. The deceased's mother was Mandy B and her father was Desmond M (deceased).

g. The deceased lived at an address in B Court, Katherine in the Northern Territory of Australia.

54. On all of the evidence received, I have no recommendations to make in relation to this death, however I do have one comment as a result of the evidence tendered before me and that is in relation to the fact that the medical staff at the Katherine Hospital did not immediately report this death to me. It is clear from the materials tendered before me that this death was reported as a result of the actions of Mr E. The KH records show that the medical staff involved believed that this was not a reportable death to the Coroner.

55. This is despite the fact that they were aware that Miss M was a child subject to a protection order, and as such was a child who was, immediately prior to her death, a "person held in care" as that term is defined under the Act. As such the reporting of her death to me is **mandatory**. In my view it is important that continuing education be provided to all medical professionals that if a person dies who is in care at the time of their death then there is a ***legal responsibility*** upon the shoulders of those medical professionals to report the death to me ***despite the death being by natural causes***.

56. On this occasion I do not consider it necessary to make a recommendation to that effect, but I do hope that by providing this comment a reminder is given to all relevant persons as to the legal requirements imposed for the reporting of such deaths.

Dated this 18th day of December 2013.

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GREG CAVANAGH
TERRITORY CORONER